

The Israel Penn International Transplant Tumor Registry

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Abstract

The Israel Penn International Transplant Tumor Registry is literally the world's premier repository of information on patients who have developed malignancies after organ transplants. The administrators of the Registry not only collect information but also provide consulting services based on the accumulated knowledge that the Registry contains. By creating a secure Web-based front end, we have made it possible for the Registry to keep pace with its burgeoning international caseload.

Problem

Over the course of three decades, the late Dr. Israel Penn collected data on more than 15,000 transplant-related malignancies. The information he collected has been used in over 400 presentations, more than 400 publications, and numerous chapters in medical publications. As such, it is the premier data collection of its kind.

The legacy left by Dr. Penn has posed a challenge of how to continue to collect transplant tumor data at a time in which transplant procedures and technology have increased, not only in the United States but throughout the world. It is no longer feasible for a few individuals to record this vital information by hand. A means for giving transplant centers the opportunity to contribute to this significant knowledge base was needed.

In addition, the administrators of the Israel Penn International Transplant Tumor Registry (IPITTR) needed more efficient and accessible mechanisms for providing consultative assistance, in an effort to positively impact the quality of care available to organ recipients who develop transplant-related malignancies.

Purpose

To meet this need, the Institute for Health Policy and Health Services Research (IHPHSR) developed a secure, Web-based registry which now facilitates entry of tumor data by transplant centers throughout the world. In time, the registry database will also incorporate historical case data. To compliment the online registry, a Web-based consultation form was added to allow medical professionals in the transplant community to consult with the IPITTR.

Transplant tumor data. The system provides Web forms to collect and maintain data on patient demographics, transplants, rejection episodes, immunosuppression adjustments, malignancies, chemotherapy and immunotherapy regimens, radiation treatments, surgeries, and patient status updates. The "controlled vocabulary" of the Registry can be managed by the IPITTR staff. Coded values greatly enhance the ease of querying the data for research purposes. Transplant centers gain access to the online registry by request to the IPITTR. Patient data follow-up reminders are automatically e-mailed by the system to participating centers on a scheduled basis.

Consultation. Medical professionals can request consultation from the IPITTR by entering de-identified patient data into a secure Web form. The information is stored in a database, and a confirmation e-mail is sent to the requestor, along with a unique consultation ID number that can be used to provide follow-up information. Consult request notifications are automatically e-mailed by the system to IPITTR staff.

24 x 7 x 365 secure internet access. The IHPHSR's HealthNet Gateway portal provides round the clock, secure, 128-bit encrypted access to The IPITTR system from any location with access to the internet.